

## Experiences of people with dementia in Pakistan: Help-seeking, understanding, stigma, and religion

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Title:

**Experiences of people with dementia in Pakistan: Help-seeking, understanding, stigma, and religion**

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## Abstract:

**Background and Objectives:** The prevalence of dementia will increase in low and middle income countries like Pakistan. Specialist dementia services are rare in Pakistan. Public awareness of dementia is low, and norms about family care can lead to stigma. Religion plays a role in caregiving, but the interaction between dementia and Islam is less clear.

**Research Design and Methods:** Qualitative interviews were carried out with 20 people with dementia in Karachi and Lahore. Interviews were conducted in Urdu, translated to English, and respondents' views on help-seeking experiences, understanding of diagnosis, stigma, and religion were analysed thematically.

**Results:** Although some people with dementia understood what dementia is, others did not. This finding shows a more positive perspective on diagnosis in Pakistan than previously thought. Help-seeking was facilitated by social and financial capital, and clinical practice. Stigma was more common within the family than in the community. Dementia symptoms had a serious impact on religious obligations such as daily prayers. Participants were unaware that dementia exempts them from certain religious obligations.

**Discussion and Implications:** Understanding of dementia was incomplete despite all participants having a formal diagnosis. Pathways to help-seeking need to be more widely accessible. Clarification is needed about exemption from religious obligations due to cognitive impairment, and policy makers would benefit from engaging with community and religious leaders on this topic. The study is novel in identifying the interaction between dementia symptoms and Islamic obligatory daily prayers, and how this causes distress among people living with dementia and family caregivers.

## **Introduction**

### **Background and objectives**

In 2015 there were estimated to be 46.8 million people with dementia worldwide, which will reach 131.5 million in 2050 (ADI, 2015). Over the next few decades the increase will be greater in low-and-middle income countries (LMIC) than in high income countries, due to faster ageing of the population and growing diagnostic expertise (ADI, 2015). Dementia has become a global health priority (WHO, 2017).

Timely diagnosis is important to access care, and because it explains distressing symptoms and enables future planning (ADI, 2011). Barriers to diagnosis include low awareness and stigma leading to concealment of symptoms (ADI, 2011, 2012). In Pakistan, these barriers are exacerbated by the low literacy level (45%) (Awan et al., 2015), and scarcity of services (Khan, 2014). Furthermore, the expectation in Pakistani culture to provide family care is high and acts as a barrier to help-seeking (Ali & Bokharey, 2015, 2016).

Little is known about the prevalence and experience of dementia in Pakistan. The 10/66 research project carried out population-based research into dementia in LMIC (the name 10/66 refers to the fact that although 66% of people with dementia live in LMIC, only 10% of population-based research was carried out there), but Pakistan was not among its research sites (Prince, 2010). The experience of older people in Pakistan merits special attention because of the country's low ranking in the Global AgeWatch Index (ranked 92 out of 94 countries) (Zaidi, 2013).

This paper is part of a larger study aiming to explore the experiences of dementia in Pakistan from four perspectives: people with dementia; their family caregivers; the general public; and key informants from the policy and practice arenas. This paper presents the findings from interviews with people living with dementia.

### **Conceptual framework**

The way that people conceptualise a disease affects decisions to seek outside help, how people are viewed by society, and coping strategies. People's understanding of disease is shaped by norms and attitudes (which are culturally bound) as well as experiences (which are context-specific) (Adamson, 2001; Nielsen & Waldemar, 2016). Dementia can be perceived in a variety of ways, from the traditional biomedical model to the psycho-social and social-gerontological models (Innes & Manthorpe, 2013). For this study, dementia is conceptualised as an incurable, progressive organic brain illness, that is not a normal part of ageing, but one where the person with the illness is able to live a fulfilling life if enabled to do so by society. Kleinman's explanatory model shows how lay

models of a particular health condition must be engaged with in order to achieve a satisfactory outcome (Kleinman, Eisenberg, & Good, 2006). For the lay person, adopting a particular perspective on dementia has particular consequences. Perceiving dementia to be a normal part of ageing means that the individual is conceptualised as healthy and no special help is required (Næss & Moen, 2015), which could be a coping strategy. On the other hand, perceiving dementia to be a mental illness is a stimulus for accessing health services, but also can lead to fear of stigma from others (La Fontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007). Blaming the individual for their dementia implies that it is the individual's responsibility to improve their own situation; a form of coping for family members. Finally, a social norm that family care ought to be provided can lead to strong pressure to continue caring without outside help, and therefore burden (Qadir, Gulzar, Haqqani, & Khalid, 2013). All of these scenarios are likely to delay accessing health and support services.

It has been argued that some researchers over-use the term 'culture' to explain differences in illness experiences between ethnic groups, and there has been a call to draw out the aspects that are religious in nature (Regan, 2014). A frequent finding from the literature on ethnicity and caregiving is of religion being used as a coping mechanism, or as a justification for caregiving (Lawrence, Murray, Samsi, & Banerjee, 2008; Merrell, Kinsella, Murphy, Philpin, & Ali, 2005; Weisman de Mamani et al., 2017). However, those findings are from a range of religious and country contexts, and not unique to any religion. One focus of this paper is on the aspects of dementia experience specific to Islam (e.g. obligatory daily prayers), rather than those that are shared regardless of religion (e.g. a religious obligation to care) which have been well-reported elsewhere (Qadir et al., 2013). This focus will more specifically identify the ways dementia is experienced by Muslims.

### **Pakistanis, South Asians, and dementia**

Due to the sparse literature from Pakistan, it is helpful to consider transferable knowledge from research with the Pakistani diaspora (e.g. in UK, Canada, and Scandinavia). Researchers commonly group Pakistanis with people from the whole Indian Sub-Continent, referred to collectively as 'South Asians'. The diaspora, especially first-generation migrants, experience additional challenges compared to their counterparts in Pakistan, including language barriers, culturally insensitive services, and discrimination. These factors make access to dementia care complex even if services are widely available. Giebel and colleagues (2015) argue that South Asians experience similar barriers to accessing mental health services in a variety of countries, and that the literature from one country is transferable to another. Common topics in the literature are understanding of dementia, stigma, and care pathways.

Data gathered from people with a diagnosis of dementia and their family caregivers in Pakistan reveal that understanding of dementia is low. Among people from Karachi who had dementia or were caring for someone with dementia, only half were aware of the diagnosis (Khan, Khan, Khan, & Najam, 2017). Similarly, South Asian carers of people with dementia in the UK reported not being familiar with the term dementia before their family member was diagnosed (Adamson, 2001; Bowes & Wilkinson, 2003).

Dementia is frequently thought to be a normal part of ageing in Pakistan (Qadir et al., 2013), and among South Asians in the UK (La Fontaine et al., 2007; Turner, Christie, & Haworth, 2005), in Norway (Næss & Moen, 2015), and in Canada (McCleary et al., 2013). The understanding of the causes of dementia was poor, with attributed causes including a contagious disease or tension due to a family rift (Qadir et al., 2013), past actions of the diagnosed person indicating blame (Adamson, 2001; La Fontaine et al., 2007; McCleary et al., 2013), stress or shock (Turner et al., 2005), the evil eye (Bowes & Wilkinson, 2003; MacKenzie, 2006), not praying (MacKenzie, 2006), or lack of family care (La Fontaine et al., 2007). However, some participants drew on the biomedical model of dementia (Adamson, 2001).

Explaining the diagnosis to the person with dementia and their carer is recommended in the UK (DH, 2009). Similarly, guidelines for clinicians in Pakistan recommend that the diagnosis and prognosis should be explained to the carer (Ahmad et al., 2013). No mention is made in these guidelines of revealing the diagnosis to the patient, however. Despite the guidelines, the studies above imply that the information was not conveyed clearly enough.

Giebel et al (2015) conducted a literature review of factors that impede access to mental health services for South Asian older people in the UK, US, and Canada. The review found that “South Asian culture” stigmatised mental illness, relating it to a religious punishment. This inhibited access to services, because family members chose to care for the individual at home for fear of stigmatisation. In the UK, South Asian carers reported that the whole family was stigmatised if somebody had dementia, leading to concealment of the person with dementia (MacKenzie, 2006). One cause of stigma was fear that the person with dementia could give the disease to others through magic. Pakistanis in Denmark were found to have more stigmatising attitudes than other ethnic groups towards dementia (Nielsen & Waldemar, 2016).

People from minority groups are typically less likely to use dementia services (Giebel et al., 2015; McCleary et al., 2013). In Canada, dementia services were accessed through several pathways, including referral from medical practitioners seen for a different condition, advice from family members who were health practitioners, or after a crisis (McCleary et al., 2013). In Scotland,

diagnosis was obtained after seeking help from the general practitioner (GP) for memory loss, or when the GP independently recognised dementia symptoms while being consulted for another condition (Bowes & Wilkinson, 2003).

Access to care depends on availability, which is patchy in Pakistan (Khan et al., 2017). There is only one neuropsychiatrist specialising in dementia in Pakistan (Khan, 2014; Khan et al., 2017). In 2014 it was reported that there were only two dementia clinics, one day care centre, and no residential care facilities suitable for dementia in Pakistan (Khan, 2014). Low levels of awareness of dementia among medical practitioners in Pakistan have also been reported (Ahmad et al., 2013). A consequence of low awareness among physicians is difficulty in obtaining diagnosis and treatment.

As commonly found across the world, the majority of day-to-day care for people with dementia in Pakistan is provided by family (Ali & Bokharey, 2015), sometimes supplemented by paid attendants. In the UK, South Asian older people were more likely than white participants to think that family should be the sole providers of care (Turner et al., 2005). Other UK studies have found that a sense of care as obligatory has been linked to Islam (Bowes & Wilkinson, 2003; MacKenzie, 2006). In Pakistan it has been reported by family carers that failure to care would be punished, and fear of God was referred to (Qadir et al., 2013). Furthermore, the use of institutional care in Pakistan was thought to be sinful and unlucky (Qadir et al., 2013), and in the UK was viewed by South Asians as a “living hell” and as something only white people would use (Bowes & Wilkinson, 2003: 390).

### **Obligatory daily prayers in Islam**

Although the symptoms of dementia are not determined by religion, there may be specific ways in which they can cause distress among Muslims. Muslims are expected to pray five times a day at times determined by sunrise (Hafiz, Dzulkhairi, Shamsir, & Abu, 2016). The person with dementia’s deteriorating sense of time orientation could affect their knowledge of when to pray. Prayers are conducted facing towards Mecca. As people with dementia lose the ability to orientate themselves in space, locating the direction of Mecca might become difficult. A person is expected to ritually wash before prayers (Hafiz et al., 2016), but dementia affects the ability to perform basic tasks such as bathing. Prayers may be performed in an appropriate place. In Scotland a Muslim carer reported that their house was dirty due to the person with dementia’s incontinence, and was no longer an appropriate place for prayers (Bowes & Wilkinson, 2003). Verses of the Quran are recited, most commonly from memory. In addition, there are a specific number of rakats (an act of kneeling and prostration) one should carry out for each prayer time (Hafiz et al., 2016). Memory loss, one of the earliest developing symptoms of dementia, may affect the ability to remember how many rakats have been completed, and the ability to recite verses. A Pakistani Muslim man with dementia in the

UK reported that he had ceased attending mosque “for fear of ‘doing wrong’ during worship” (Regan, 2016: 712).

Prayers are meant to be conducted with a clear mind. This usually refers to being free from alcohol or drugs, but it has also been extended to refer to being free from cognitive impairment according to Malaysian research (Tumiran et al., 2018). However, it is not clear if this exemption from prayers is accepted beyond Malaysia. Furthermore, people with dementia may wish to continue praying as long as they can, even if they are exempt. In summary, the symptoms of dementia mean that people with dementia may not be able to follow all the rituals around praying. This difficulty fulfilling the expectations may lead to guilt and distress among the person with dementia and their family carers.

### **Research focus**

As this was an exploratory qualitative study formal hypotheses were not applied from the outset. Instead, we set out to explore respondents’ experiences with help-seeking, understandings of dementia, experiences with stigma, and the role of religion among people with dementia in Pakistan.

### **Design and Methods**

The findings in this paper are part of a larger project on understandings and experiences of dementia in Pakistan, carried out by a UK based research team and project partners in Pakistan. This paper focuses on interviews with people living with dementia.

There were two urban research sites in Pakistan: Karachi and Lahore. In Lahore the participants were recruited through Alzheimer’s Pakistan (a non-governmental organisation providing information, training, and services for dementia), while in Karachi the participants were recruited through a hospital-based dementia clinic. Purposive sampling was used to identify patients who had a recent diagnosis of mild dementia, and a balance of men and women was sought in the two locations.

Ten interviews were conducted in Karachi (4 female, 6 male), and ten in Lahore (5 female, 5 male); their characteristics are set out in Table 1. All interviews involved one person with dementia, many of whom were accompanied by at least one caregiver. The caregiver was usually a family member, though in one case they were a paid live-in assistant. Although the focus of the interviews was on the experiences of the person living with dementia, in some cases the caregivers helped to answer. This happened where the person with dementia was unable to recall or articulate the answer. This does not undermine the aims of this project, because the focus of the interviews remained on the experiences of the person with dementia. In other words, the questions were about the lives of the



person with dementia rather than the impact dementia has had on the caregiver. This can be thought of as similar to a proxy-report, which has an important role in understanding the experiences of people with dementia who may not be able to share their experiences due to memory or language problems (Smith et al., 2005). Caregivers can provide a good account of the person with dementia's experience, however there are cases where caregivers provide a more negative account than the person with dementia would (Neumann, Araki, & Gutterman, 2015). Bearing this caveat in mind, a minority of the quotations presented here are from the caregiver answering on behalf of the person with dementia, and these are clearly labelled.

*[Insert Table 1 about here]*

The semi-structured interview guides, participant information sheets, and consent forms were drafted in English by the research team in the UK, translated into Urdu, and tested for ease of comprehension in Pakistan through a patient and public involvement process. The translation was checked for accuracy by an Urdu-speaking member of the UK research team. The interview questions asked about how participants first recognised they had memory problems, their understanding of what caused their memory problems, how they feel about it, how their family and people in the neighbourhood have responded, their access to medical services, any changes they have made to their lives, and their advice for other people with the same issues.

Ethical approval was obtained from both a UK and Pakistani University. Pilot interviewing was observed by members of the UK research team during a site visit to Pakistan. Data were collected in Urdu by project partners, and translated into English for analysis.

Thematic analysis (Braun & Clarke, 2006) of the interviews was carried out in English by the UK research team, drawing on a pragmatic paradigm. An open coding process was facilitated by NVivo 11 software. Coding began at the descriptive level, and nodes of similar meaning were grouped under higher-order category parent nodes. A mixture of anticipated and unexpected concepts were coded, following a combination of deductive and inductive perspectives. For example, the node *Understanding of diagnosis* was created because of the research aims, while the node *In God's hands* was unanticipated. As a result of the combined deductive and inductive approach the themes reported in this paper are linked to the research aims and interview questions, but have also been directed by the data (e.g. the deductive parent node *Pathways to diagnosis* has inductive child nodes of *Serendipity*, *Already in the system*, and *Sought help for dementia symptoms*).

Initial coding was agreed by all four members of the UK research team. Once a coding scheme was agreed, coding was completed by the first author. The first author's emerging analytical thoughts

were discussed and refined within the team using a combination of email, face-to-face discussions, and formal team meetings. Analysis of interview data collected by another person poses difficulties; since the analyst was not present during the interviews they did not co-create the data.

Furthermore, in this case the data were translated into English and so some of the original nuance of meaning may have been lost. In order to overcome these difficulties, the first author discussed potential interpretations of the text with co-authors familiar with the Pakistani, Urdu, and Islamic context. The original interviewers were also consulted for interpretation of the text. Differences in interpretation were resolved through this technique.

## **Results**

The themes include how participants obtained their diagnosis, their understanding of the meaning of their diagnosis, their experiences of stigma, and the interplay between religion and symptoms.

### **Pathways to diagnosis**

Obtaining a diagnosis of dementia is difficult even in countries with dementia policies and well-established mental health services. This section explores how the 20 people living with dementia were diagnosed.

There were three main pathways to diagnosis, which were named 'Sought help for dementia symptoms', 'Already in the system', and 'Serendipity'.

As the name suggests, people who sought help for dementia symptoms had the most straightforward pathway. Either the person with dementia, or their caregiver, recognised there was something not right about the symptoms, and they accessed health services often with their family physician as a starting point. In some cases these participants were highly educated, or had doctors in the family, leading to familiarity with medical concepts and services. This demonstrates the importance of social and financial capital.

*"Caregiver: Mother is very conscious about this matter. She has got a lot of knowledge about every field. She reads whole newspapers, medical surveys ... When she forgot, she said that 'There is something going on in my brain'. Then she said, 'Take me to the neurologist'. She declared that 'I am having this problem so I should consult someone'. She has the knowledge." (Caregiver of person with dementia 01, Lahore)*

Those termed 'Already in the system' also recognised the unusual nature of the symptoms, but these participants were familiar with mental health services. Some of them had pre-existing mental

health issues, while others had family members with mental illnesses, and knew about Aga Khan Hospital's psychiatric department in Karachi. This meant it was easier for this group to access services for dementia.

*"Interviewer: Can you tell me about how you got in touch with the clinic about your memory?"*

*Person with dementia: My daughter was already treated by Dr [name] in Aga Khan so we thought to consult for me...as well."* (Person with dementia 06, Karachi, male)

The third group, called 'Serendipity', were guided towards services by outside influence. Typically, they sought medical help for a different health problem, and the health professional recognised there was an additional problem and advised them to seek out a specialist. This group did not recognise the dementia symptoms as something unusual that required mental health services. Nonetheless, they successfully obtained the diagnosis.

*"Interviewer: What problems did you face?"*

*Person with dementia: I had a severe headache ... Then, I saw a doctor. The doctor offered treatment: take this [painkiller], take that; no improvement occurred .... When all this increased very much then one doctor said: She has a psychological disease and you must immediately take her to a reputed psychologist so that doctor will give medicine to stop these symptoms."* (Person with dementia 01, Karachi, female)

In summary, knowledge of medicine and medical services facilitated the pathway to diagnosis. Those without this knowledge had to rely on symptoms being recognised by doctors.

### **Understanding of diagnosis**

All of the people with dementia in this project had a diagnosis of dementia. We could therefore expect them to be among the most well-informed people about dementia in Pakistan. However, the data show that some of the people with dementia did not know that they have dementia, while some of the caregivers did not fully understand what dementia means. Conversely, some of the participants had a biomedical understanding.

Many of the people with dementia and their caregivers had a biomedical understanding of the causes of dementia, relating it to stroke, recognised that it is not a natural part of ageing, and that the symptoms will get worse.

*"Interviewer: What is this disease about? Do you know anything about it?"*

*Person with dementia: Yes she [the doctor] told me.*

*Interviewer: What?*

*Person with dementia: That it is related to forgetting things. [The doctor told me] that with time slowly, slowly the patient's condition happens to be such that they even forget that they have to go to the washroom. This is how she explained it to me."* (Person with dementia 03, Lahore, female)

On the other hand, several people with dementia attributed it to various causes, including shock, depression, stress (referred to commonly as 'tension'), old age, or thinking too much.

*"Interviewer: What has happened to you? What are the issues?"*

*Person with dementia: Just my confusion is increasing day by day due to over thinking."*

(Person with dementia 09, Karachi, male)

Similarly, several caregivers attributed the causes of dementia to old age, shock, tension, or bereavement. Some caregivers had a spiritual view of dementia, arguing that the symptoms were caused by 'black magic', or part of preparing for the next life.

*"Caregiver: He is getting ready for the next world. The next world is the world of imagination and when they start living in the world of imagination then they get tired of everything of this world and it becomes useless and they start forgetting things of this world."* (Caregiver of person with dementia 07, Lahore)

Despite a formal diagnosis of dementia being made, participants varied in their understanding. This may indicate that the diagnosis was not explained to them in the clinic, or that participants' lay conceptualisation of illness is preferred over the biomedical model.

## **Stigma**

The interviews asked how other people have responded to the dementia. Negative experiences from community members were unusual, and only one person (a caregiver) had experience of neighbours treating the person with dementia badly; some people make fun of the symptoms. Two people speculated that neighbours might make fun of them behind their backs, but they had not actually experienced this.

In contrast, most participants reported being treated particularly well by neighbours. Several people said that they were helped by friends and neighbours because of the symptoms. For example, one person was helped home by neighbours when they got lost coming back from the mosque, while another was helped by a shopkeeper.

*"Interviewer: What happens when you forget groceries at the store?"*

*Person with dementia: ... The shopkeeper knows that I forget. At times [the shopkeeper] used to come to my home [with the forgotten items].” (Person with dementia 04, Lahore, male)*

Community members, therefore, were mostly very positive towards the people with dementia. However, such was not always the case within families. Some family members became angry because they thought that the person with dementia was pretending.

*“Person with dementia: I tell people that I have this disease, they don’t trust me.*

*Caregiver: Her brothers disagree.*

*Person with dementia: My brothers and their wives say that I am totally fine.” (Person with dementia 03, Lahore, female)*

Others reported that their family members were kind, respectful, and supportive, and this attitude was linked by participants to being educated. Overall, there was greater negativity from family members than from neighbours or community members. This could reflect carer stress, or possibly people with dementia interacting less frequently with community members than with family.

## **Religion**

An unanticipated issue arising from the interviews was the difficulty caused when dementia symptoms interfered with obligatory daily prayers. Some people with dementia explained how they forget to pray, or during prayers their mind wanders and they have to start again. In particular, a difficulty with orientation in time interferes with knowing the correct time of day to offer prayers.

*“Person with dementia: Sometimes I don’t have any idea that it’s morning. To offer prayer is also very difficult. I usually ask a family member ... ‘Have I offered Zuhr [second daily] prayer?’ If they see me while offering they say ‘Yes, you have done it’.” (Person with dementia 10, Karachi, female)*

Two others explained how they had forgotten the parts of the Quran that they had previously memorised.

*“Person with dementia: Like in the Quran I did hifz [memorizing]. There are very long surat [verses] in the Quran so before that [the dementia] I have remembered all the surats but now I just forget.” (Person with dementia 07, Karachi, male)*

These participants’ insight into how their memory problems affect their ability to perform daily prayers was very upsetting to them.

In addition, one caregiver reported how the person with dementia repeatedly asked their family members whether or not they have prayed yet, while another refused to pray when told it is time because she believed the caregiver was lying. Some caregivers reported that the person with dementia cannot remember the number of rakats that should be performed and have to ask. One person with dementia tried to recite verses from the Quran in the bathroom, which is an inappropriate place to pray. Another caregiver explained how difficulty with orientation in space means the person with dementia was unable to lay their prayer mat correctly towards Kabbah [shrine in Mecca].

*“Caregiver: I have this issue that I have to remind him to pray.*

*Interviewer: Does he pray alright?*

*Caregiver: Sometimes he offers two rakats, sometimes one.*

*Interviewer: Does he find out the direction of Kabbah?*

*Caregiver: No, He does not know that. I prepare the prayer mat for him. If he does it he doesn't do it right.” (Caregiver of person with dementia 01, Lahore)*

Other ways in which religion was discussed included (i) as a reason for providing informal care, (ii) as a strategy for coping with distressing symptoms, and (iii) trust that whatever happens is according to God's will. In many ways these findings are similar to those of past research and are not specific to Islam. However, the distinct aspects in which they were voiced among our participants tended to focus on the topic of fear. One caregiver explained that the reason they look after their relative with dementia is *"because of fear of God and our good upbringing"* and because *"Allah is still watching"* (Caregiver of person with dementia 02, Lahore). This indicates that in this case caregiving is not a duty taken on proudly (as found in the cultural justifications of caregiving literature), but instead is shouldered in fear of God's retribution.

In summary, religion shaped participants' response to dementia in some ways (e.g. justification for caregiving, fatalistic approach to illness). However, when dementia came into conflict with fulfilling religious obligations, challenges occurred that remained unresolved for these participants.

## **Findings summary**

Overall, the findings reveal that the participants with high social capital were more easily able to recognise symptoms and seek appropriate help. Participants without this capital still received a diagnosis, but through a more complicated process. Lay understandings of dementia held

importance for participants despite engaging with medical services. Stigma from the community was less common than might be expected from the literature. Finally, the practice of Islam was seriously impacted by the symptoms of dementia.

### **Discussion and Implications**

This paper adds important insights to the literature on dementia in LMIC like Pakistan. Although services are few and accessible only to those with resources (Khan, 2014), these interviews demonstrate that it is possible to successfully obtain a diagnosis of dementia in Pakistan. A segment of the population already had awareness of dementia and other mental illnesses, facilitated by education and family connections, and this group might be expected to obtain a diagnosis. More encouragingly, other participants who did not recognise their symptoms were identified by health professionals and referred on to specialist services, similar to research in Scotland (Bowes & Wilkinson, 2003). This demonstrates that there are health professionals in Pakistan who have the knowledge to recognise dementia, which is contrary to the past finding that medical professionals in Pakistan are untrained in dementia (Ahmad et al., 2013). Although the present study is qualitative and not intended to generalise to the whole population of Pakistan, it does provide a more positive perspective on accessing dementia care than previously thought. Having said that, there are likely to be people who are not diagnosed and have been missed by healthcare professionals, and a national screening programme would be required to understand the scale of this problem.

Following the Kleinman model (2006), asking people what they think was the cause of their disease can help to provide better care. A common finding from literature in Pakistan, and from South Asians in other countries, is unfamiliarity with dementia before diagnosis, and a belief that dementia symptoms are a normal part of ageing (Adamson, 2001; McCleary et al., 2013; Qadir et al., 2013). The clinical guidelines in Pakistan recommend that doctors tell the caregiver about the diagnosis and prognosis, but do not mention telling the person with dementia (Ahmad et al., 2013). As all people with dementia in the present study had a diagnosis, it might be anticipated that awareness of dementia would be high. However, the data show that understanding of the causes and course of dementia was mixed. Some participants adhered to a biomedical model, which functions to give them access to health and support services (Næss & Moen, 2015). Others argued that dementia was a normal part of ageing, which allows them to avoid stigma and blame. Some participants attributed their biomedical understanding of dementia to their educational level and family members with a medical education. Participants spoke about 'uneducated' people being more likely to misunderstand the symptoms, or treat the person with dementia poorly. This finding demonstrates

the importance of social and human capital in obtaining the treatment for dementia, and shows how this conceptualisation of dementia serves to contrast themselves favourably to others in society. All of the participants were from an urban setting and fairly affluent, so it is possible that more rural, poorer participants would not have the same level of social and human capital and thus be disadvantaged in accessing dementia care.

Previous research has reported high levels of stigma around dementia in Pakistan (Khan et al., 2017), and among South Asians in other country contexts (MacKenzie, 2006). In the present study stigma was less prevalent. Participants reported being treated kindly in the neighbourhood, where people ensured the person with dementia got home safely or received forgotten groceries. People with mild dementia did not seem to be shunned by society in our sample, which suggests forgetfulness or disorientation were not behaviours that attracted stigma. It was less clear from our data if symptoms of more severe dementia would be met with the same kindness. Contrasting with the helpful neighbours, participants reported being treated poorly by family members. This could potentially be linked to family members seeing the person with dementia more frequently and at the more severe stages. This closer contact might lead to frustration on both sides (Ali & Bokharey, 2015), especially if family members do not fully understand the reasons for symptoms.

The issue of religion was particularly illuminating. Previous research on Muslims and dementia has touched upon the idea of incontinence disrupting the cleanliness necessary for prayers at home (Bowes & Wilkinson, 2003), or the fear of doing something wrong while in public at mosque (Regan, 2016). The present data demonstrate the impact of symptoms of dementia on the obligatory daily prayers of Islam. These included difficulty with counting rakats, orientation in time to know when to pray, orientation in space to know the direction of Mecca, and judgement about appropriate places to pray. All of these issues are specific to Islam. Previous research shows similarities between religions in terms of drawing on religion as a reason to provide care, or to cope with carer burden (Dilworth-Anderson, Williams, & Gibson, 2002; Regan, 2014). However, the present study is the first to our knowledge to identify the interaction between dementia symptoms and Islamic daily prayers, and how this causes distress among people living with dementia and family caregivers. Some caregivers assisted their family member to pray by laying the prayer mat, or reminding them when it was time to pray. This kind of enabling behaviour was usually responded to well by people with dementia, and may be an important avenue for intervention in caregiver support.

It has been argued that people with cognitive impairment are exempt from daily prayers (Tumiran et al., 2018). No mention of an exemption from prayers was made by participants, so it does not seem to have been part of the discussion about dementia with their physicians. The authors of the present



study contacted an Alim (a scholar of Islam) who confirmed that a person who does not have control over their mind is exempted from following the obligatory prayers. However, it is important to be mindful that people of different denominations within Islam will have different interpretations of their religion. Having said that, the exemption ought to be acceptable in Pakistan because the Alim consulted was from Pakistan and familiar with the way Islam is practiced in that country. However, there is no known formal position taken by a religious institution respected by all denominations in Pakistan.

The participants in the present study did not know about the exemption, and it caused them guilt and distress when the prayers were missed or performed incorrectly. We therefore recommend that faith leaders in Pakistan engage with psychiatrists, neurologists, and geriatricians, and provide to the public information on obligations on praying, and clarity on what dementia is and what should be done about it. Such a strategy has previously proved effective in increasing the take-up of polio vaccinations in Pakistan (National Emergency Operations Centre, 2017). Having said that, it could also be recommended that people with dementia are enabled to continue to perform the prayers as long as they wish, as they may gain comfort from the routine and spirituality. Previous research shows the importance of a familiar routine in dementia care (Porock, Clissett, Harwood, & Gladman, 2015), and that meditation is beneficial to cognition (Chételat et al., 2018). Caregivers could enable prayers by assisting with ablutions, prayer mat placement, and audio recordings of Quranic verses. In cases where guilt and stress are increasing, however, guidance about exemption may be helpful.

### **Limitations**

The limitations of the present study include the small sample. However, the purpose of this qualitative research was not to generalise, but instead to provide insight into a little-studied population and suggest avenues for future research and policy intervention. This goal has been achieved. Having said that, the similarity of findings with previous studies in Pakistan and beyond indicates transferability. Secondly, the sample achieved was quite wealthy and well-educated. There may have been quite different results in a more mixed socio-economic population. A third limitation is that only some of the research team were involved in data collection. The research team has done its best to overcome the distance between ourselves and the original data by dissecting issues of interpretation of text, and members of the research team have the advantage of familiarity with Islam, Urdu, and Pakistan. In future research it would be advantageous to conduct the analysis in Urdu, before translating into English, but this was not logistically possible in the present study.

### **Recommendations**

This paper has presented new data on the experience of people living with dementia in Pakistan, including their sometimes complex pathways to diagnosis and understandings of their diagnosis. Valuable new knowledge about the interaction between dementia symptoms and obligatory prayers in Islam has been generated. Recommendations for practice and policy are to continue to educate clinicians to recognise signs of dementia and refer on to specialist services appropriately, and to improve access to specialist services for people of limited financial means. Enlisting the help of religious leaders and clinical experts in increasing public understanding of dementia, where to seek help, and what it means for daily life, would be advantageous. Finally, more research into dementia prevalence and treatment effectiveness in Pakistan is needed, especially in rural areas that typically have less access to care and awareness campaigns.

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*Table 1: Demographic characteristics of the participants*

<b>Interview location</b>	<b>Participant number</b>	<b>Sex</b>	<b>Age</b>	<b>Tenancy status</b>	<b>(Former) Occupation</b>
Karachi	01	Female	80-89	Owner Occupier	Housewife
Karachi	02	Male	60-69	Not known	Business
Karachi	03	Female	50-59	Owner Occupier	Housewife
Karachi	04	Female	70-79	Not known	Artist
Karachi	05	Male	70-79	Not known	Business
Karachi	06	Male	60-69	Renter	Not known
Karachi	07	Male	60-69	Owner Occupier	Mosque administrator
Karachi	08	Male	70-79	Owner Occupier	Not known
Karachi	09	Male	60-69	Owner Occupier	Business
Karachi	10	Female	70-79	Owner Occupier	Pharmacist
Lahore	01	Female	70-79	Not known	Housewife
Lahore	02	Female	70-79	Owner Occupier	Teacher
Lahore	03	Female	40-49	Renter	Housewife
Lahore	04	Male	90-99	Owner Occupier	University faculty
Lahore	05	Male	60-69	Not known	Contractor
Lahore	06	Male	70-79	Owner Occupier	Radio worker
Lahore	07	Female	80-89	Owner Occupier	Housewife
Lahore	08	Male	60-69	Renter	Teacher
Lahore	09	Female	80-89	Not known	Housewife
Lahore	10	Male	70-79	Not known	Engineer

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## **Ethical approval**

This project was approved by the ethical review board of the University of Southampton [25793] and Aga Khan University [4819-Psy-ERC-17].